

Cystic fibrosis hit our family the way waves crescendo into a tsunami. After years and years of frustrating health issues, and test after test, I was the first in our family to be diagnosed two years ago, at the age of thirty-six. I was an extremely rare case, to have such limited disease. I felt so fortunate; at least we knew what was going on. Because cystic fibrosis is a mutation driven disease, my care team swiftly started focusing on our four children. My husband had a 1 in 20 chance of being a carrier and within weeks all of the tests had come back, he was a carrier and our 9 year old daughter and 11 year old son were diagnosed with Cystic Fibrosis. This revelation put so many things in perspective for us. Our children had endured procedure after procedure, appointment after appointment, since they were born. However, when the diagnosis comes, it is hard to be properly prepared. We reluctantly had joined the ranks of 30,000 other Americans that plagued by CF.

It is hard to detail this time in our life with words. Everything we read about CF detailed that 'children used to die before they were out of elementary school, now they live to be into their 30s'. "Live into their 30s"? Do we now have to alter our dreams to fit this predetermined schedule? Fear had temporarily taken over our lives. At this point, most days were spent crying, and nights were spent dreaming about how my children might someday drown in their own mucus.

You might think our children 'lucky' to have had normalcy during their young years; on the contrary, the late diagnosis meant we had lost precious time in the battle to protect their vulnerable lungs from dangerous germs. Our new life entails vigorous daily medications and therapies totaling about an hour for each of us, other CF patients do even more. The adjustment for the children has been extremely challenging, 11 year old boys don't like waking up to a whole new life...trust me. However, research shows us that compliance with these treatments can actually prolong life by decades, this is of course, what we are all striving for. Our families story is not unique, as a matter of fact, I'm sure if you polled your friends and neighbors, someone would know of a family battling CF.

Nate and Cady were born in California before the newborn screenings for CF were mandated. They were also fortunate to be born with Pancreatic Sufficiency, about 10% of CF patients are. The challenge with being Pancreatic Sufficient, is that many pediatricians, with out the tool of newborn screenings, base their CF suspicions on this symptom. When it is not there, and the newborn screening is not there, these children suffer for years without a proper diagnosis and none of the appropriate treatment. The years of limbo often leave their lungs in a degraded condition and their nutritional status hugely compromised. CF doctors, as amazing as they are, can not turn back the damaging hands of time. Many kids will endure constant testing, tube feedings, IV drugs, frequent hospitalizations and double lung transplants. Controlling this disease is all about prevention. Prevention that should start from birth.

Our Government has passed many laws to honor, prolong and protect life. Recent new technologies and drug approvals are giving our family and so many others, hope. Personally, I have been moved and motivated by the medical accomplishments of so many determined people and I want my children to know they are not lonely victims of

this disease, but they are warriors with an army standing behind them. Amazing scientific advances provide an opportunity to continue promoting the health of Connecticut's citizens. Science has provided an amazing tool in 'newborn screenings' and it is a natural progression that our government would take advantage of this scientific milestone for the benefit of all the children born here. I am sure that your constituents will, for centuries, reap the rewards of this mandated test. Cystic Fibrosis is a formidable opponent and demands fierce attention from everyone in its path, mandated screening is the first step in effective management of this devastating disease.